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Empowerment of Patients In Health Care and Its Impact on Their Behavior

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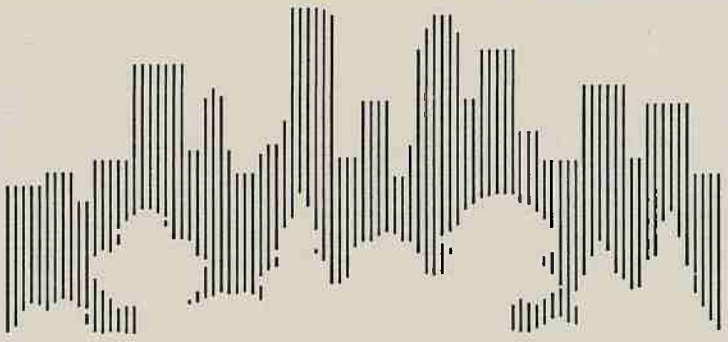

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MASTERS IN SOCIAL WORK THESIS

Laurie Dahley

Empowerment of Patients In Health Care and Its Impact on Their Behavior

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EMPOWERMENT OF PATIENTS IN HEALTH CARE AND ITS IMPACT ON THEIR BEHAVIOR

BY LAURIE CHAMP DAHLEY

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CERTIFICATE OF APPROVAL

This is to certify that the Master's thesis of:

LAURIE CHAMP DAHLEY

has been approved by the Examining Committee for the thesis requirements for the Master of Social Work Degree.

Date of Oral Presentation: April 7, 1995

Thesis Committee:

Thesis Advisor: Blanca-Rosa Egas

Thesis Reader: Vince Peters

Thesis Reader: Pauline Burthwick

DEDICATION

To my Husband, Ron,

For his words of encouragement at midnight, the many loads of laundry, for taking on the job of single-Dad, for being there in so many ways, I give to him my undying love, respect, and admiration. May I be there for him in the coming year while he writes his thesis.

To my Daughters, Kara and Emily,

It was my hope that this effort would be a lesson for them about the importance of education. Instead they taught me a lesson in love. For their understanding of the many times that Mom could not be "present" for them, for the hugs, kisses, and love they gave to me, for cheering me on I dedicate this effort and what lies ahead...

To my parents, Wayne and Naomi,

For teaching me the importance of learning and whose values and caring for others can be found between each line of this work.

ACKNOWLEDGMENTS

To my sister, **Julie**, for her physical help during this endeavor, her emotional support, and the reminder of our special bond. I love you.

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To **Blanca-Rosa Egas**, my advisor, whose support and assistance guided me through this process. She brought an understanding of what patient empowerment means and gave so much to me in the learning process.

To **Sheila**, my classmate and friend, without whom this struggle would have seemed harder, the rides longer, and the days without as much sunshine and laughter.

ABSTRACT OF THESIS

EMPOWERMENT OF PATIENTS IN HEALTH CARE AND ITS IMPACT ON PATIENT BEHAVIOR

Focus of Study: Research

Laurie Dahley

April 7, 1995

The purpose of this study is to determine if the lack empowerment in health care is demonstrated in overt negative behavior in patients. Previous research demonstrated increases in perception of pain, depression, and noncompliance with the medical regime to be common responses to the lack of empowerment. As the incenter hemodialysis population has a highly restricted medical regime, they were utilized as the subjects for this study.

An exploratory study utilizing existing data was conducted at Dakota Hospital Medical Center in Fargo, North Dakota. Nursing care plans were screened to identify the negative behavior in question for all patients currently receiving incenter hemodialysis. Educational level was also evaluated for possible impact on behavior. Findings were that the incidence of the negative behavior were high. In factoring the educational level, it was found that those of higher educational levels experienced fewer incidences of negative behavior than those with lower levels of schooling.

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SECTION I

EMPOWERMENT

GENERAL BACKGROUND

Our perception of control over our lives creates in us the sense that we can or cannot meet our basic needs. Miller et al. (1989) defines control as the individual's perception that he or she can execute (or has the potential to execute) some action that changes an aversive stimulus. Our sense of control reveals to us our ability to impact on the environment around us in order to meet the basic needs of survival. It is seen as our ability to alter events.

It has also been inferred that our perception of control over events is by far more significant than our actual level of control. In other words, the perceived control we have can impact on our behavior and response to stressors. Burger (1989) found that people generally perceive themselves to have greater control over a variety of situations than they actually have. When faced with a conflict in perception of control, events are re-interpreted by the subject in order to regain a sense of control.

Another related concept is that of information control (Burger, 1989). This refers to the process of giving a person information in order to increase a level of understanding and thereby impact on behavior. This is based on the belief that increased understanding results

in positive behaviors. This term has been referred to as "predictability" (Burger, 1989) and is quite adaptable to the health care setting. Patient education and information processing are vital components to a patient's sense of control. The basis behind these efforts is the concept of predictability.

IMPACT OF ILLNESS/HOSPITALIZATION

When entering a hospital, a patient experiences a depersonalizing environment that forces the patient to relinquish control over daily activities to professionals involved in his/her care. Schedules are focused around patient care and efficiency; not necessarily the patient. Tests are performed on the body. A cooperative patient is expected in order to complete the procedure or examination. Hospital routines are most often established with staffing and efficiency in mind, rather than individual patient needs (Taylor, 1979).

An added insult is "hospital speak", a term coined by Lynn (1993) in reference to the medical jargon which can dominate staff to patient communication. Lynn writes, "Hospital speak outwits the average individual and maintains the 'them and us' gulf. A vocabulary that can confound the ignorant is of inestimable value to the insecure and pompous." The medical terminology utilized by health care professionals does little to alleviate anxiety or clarify the concerns that lie primary to most

patients dealing with chronic illness. During the course of their interactions with health care professionals, they are consistently bombarded with jargon for which many designate their own peculiar meanings. The misinterpreted meanings often add to the depth of hopelessness that many patients feel when striving for information.

Related to these issues is our ability to avoid the debilitating feelings of helplessness that come from a perception of too little control. Folkman (1982) reported that when an individual's efforts to control the environment are repeatedly unsuccessful, the individual, not only ceases responding to the environment, but may also fail to respond in some new environments where control may be possible. This learned helplessness can become a behavior quickly adopted in the health care setting, where patients face an overwhelming structure that is not designed to allow the individual patient any significant control.

On the other hand, the supposition that increasing a sense of control will impact positively on behavior has been countered by Burger (1989). Burger found that with some patients an increase in their perception of control was more than they were able to handle. They experienced higher levels of anxiety and poorer performance on some tasks. Burger's stance is that our level of anxiety is related to the disparity between the level of control we have and the level of control we desire.

Another question then becomes, does a loss of control have a positive or negative impact on behavior? And who defines the behavior? Taylor (1979) discusses at length the impact that the role of the person labeling the behavior has on the definition of positive or negative. Health care staff may see a passive patient who remains docile to their rendering of care as positive. This same patient may be perceived negatively as abdicating vital roles important to their ego structure by the patient advocate. This study will utilize behaviors that can be objectively defined and monitored without bias.

When faced with the diagnosis of a chronic illness and a complicated medical regime, the impact of the loss of control is compounded over the time period of the illness (Mayer et al., 1990). It is vital, therefore, to convey a perception of control to the patient in order to secure a partner, rather than passive observer, to the treatment process. This perception of control impacts on the patient's self-esteem which can impede the ability to learn and process information.

END STAGE RENAL DISEASE

For the past decade, this researcher's experience has been in working with the end stage renal disease population as a medical social worker in a hospital setting. This disease requires a course of treatment in order to sustain the life of the patient afflicted with

this diagnosis (Daugirdas & Ing, 1994). Incenter hemodialysis is the most common form of treatment and the most restrictive to patient lifestyle and sense of control. The hemodialysis patient experiences a great many losses related to personal schedule, diet, fluid restrictions, and body image as part of the medical regime.

The chronic nature of this illness is noteworthy, in reference to studies that have shown negative behaviors are exacerbated in a chronic condition (Mayer et al.,1990). Being faced with multiple losses, never-ending restrictions and the uncertain future of life on dialysis, it would seem the perfect population to consider studying the impact of the lack of empowerment.

Depression is the most common mental health complication in dialysis patients (Daugirdas & Ing, 1994). One study documented that 27 percent of those hemodialysis patients studied had suicidal ideations (King, 1991). Approximately, one in every 500 dialysis patients commits suicide, with a larger number attempting unsuccessfully on one or more occasions. The connection between depression and noncompliant behavior is examined by Cohen & Tucker (1994) with their results suggesting a causal link. They also note a decline in the survival rate among those patients struggling with the negative impact of depression and noncompliance.

The incidence of an increased perception of pain is another area of interest to this researcher. Due to the chronicity of hemodialysis treatment, quality of life must certainly be questioned for the patient who views treatment as painful. Wallston (1989) demonstrated in a variety of health care setting and treatment protocols that the level of control in the situation impacted significantly on the level of pain perceived by the patient. An example of the link between empowerment and perception of pain is the patient control analgesic pump (PCA). With the introduction of the PCA pumps for pain medications following surgery, we have noted a marked decline in the amount of medication needed to address their post-surgical pain.

Past research has focused on providing patients with support to cope with the multiple losses experienced in chronic renal failure (Cohen & Tucker, 1994; Evans, 1994; Rodriguez et al., 1991; & Eddins, 1985). This researcher would suggest a re-definition of the problem. Previous approaches have defined the problem as being patient centered with energy focused on changing the patient. If re-framed to a system centered perspective the health care system becomes the focus of change. Analysis of the policies and procedures that create this environment is a more productive approach. It allows for the development of a proactive solution to the issue.

The goal of this project is to first confirm the supposition that there are negative consequences for the loss of empowerment in patients on a dialysis unit. The negative behaviors to be monitored will be depression, increased perception of pain, and noncompliance with the treatment regime. These behaviors impact on patients, families, medical staff, and society with financial and emotional costs. The financial costs include:

1. increase in staff time
2. increase in use of medications
3. increase in admission to hospitals
4. increased mortality and morbidity
5. litigation

The psycho-social costs include:

1. decreased self-esteem
2. impaired body image
3. sense of personal violation
4. learned helplessness
5. decreased quality of life
6. ineffective communication patterns

Secondly, as suggested in previous research (Mahler & Kulik, 1990; Newmann, 1994) this researcher will examine the impact that the schooling level of the patient may have on the incidence of these negative behaviors.

WHY CARE ABOUT EMPOWERMENT?

Can society afford not to examine our delivery of health care, in an attempt to enhance the empowerment of patients? The cost for our inactivity in this area has cost much in monetary and emotional terms.

Health care reform has taken on great importance in our current efforts to address the fiscal and emotional woes of our country. The fiscal impact that empowerment of patient in their health care experience has been well documented.

Mahler & Kulik (1990) demonstrated several fiscal benefits when patients felt a degree of empowerment. They included:

1. Shorter length of stay in the hospital
2. Fewer pain medications necessary
3. Less staff time required

With malpractice litigation impacting the medical community and our society with significant costs, Taylor (1979) suggests empowerment of patients as a solution. When the patient is an equal partner in the health care team and feels a sense of control over the treatment plan, projection of blame onto others is less likely to occur.

Noncompliance is problematic for the patient and health care team. Noncompliance is responsible for significant staff time, admissions and re-admissions to the hospital, and the ultimate loss in increased mortality (King, 1991). The societal costs for noncompliant

behavior consist of additional health care dollars due to the aforementioned consequences, while the emotional losses/costs relate to the lost potential of the individuals who choose this form of behavior in which to deal with the stress of illness. The emotional costs associated with noncompliant behavior are:

1. decreased self-esteem
2. diminished body image
3. diminished performance in family and societal roles
4. emotional burden of medical professional who adopt a stance of responsibility for patient behavior.

The emotional benefits to the patient and the staff involved in their care must also be weighed. The burden that medical professionals now bear would be greatly lifted if the patient were seen as a team member, rather than a body for whom staff make decisions and render treatments upon. The benefits to patients, who participate more fully in a process so entirely encompassing their being, produces a healthier, more proactive patient. Taylor (1979) also addresses the savings in monetary and human suffering if communication between medical staff and patients were more effective. This could only be achieved if the power structure of the relationship is modified to allow for free flowing communication and information sharing.

The reasons to pursue a better understanding of empowerment are obvious. The motivation to examine our health care system to enhance the degree of empowerment felt by patients is substantial.

SECTION II

LITERATURE REVIEW

SUPPORTING RESEARCH

Research supporting the belief that lack of empowerment results in negative behaviors has primarily focused on the acute patient population. Mahler and Kulik (1990) studied the impact of control on coronary bypass patients and found that those with a sense of control and empowerment over their recovery experienced less pain, ambulated more, and subsequently had shorter hospital stays.

They also found that the educational level of the patients could be used as a predictor for their behavior. Those with a higher schooling level struggled more with the loss of control than those of a lower educational level.

Their reasoning behind these findings were that individuals with higher schooling levels were typically employed in jobs where they exercised a great deal of control over their environments and thus, the loss of control with hospitalization was much greater in comparison. They conversely felt that those with limited educational backgrounds were typically employed in manual labor or entry level positions in which they were not able to exercise any significant degree of control and thereby accepted a similar powerlessness in the hospital without a great deal of distress.

Although their reasoning appeared sound, question could be raised as to the ability to generalize throughout the population such findings. The study was conducted at San Diego Veteran's Hospital and the subjects were from an urban area. The ability to verify this finding in a predominantly rural setting would help support their reasoning.

Taylor (1979) linked the feelings of helplessness and loss of control to depression and noncompliance. She defined noncompliance as the patient's attempt to control that portion of life to which he/she are still the master. Placing this positive definition on what otherwise appears to be a negative behavior, can alter the interaction between health care professionals who are attempting to convince the patient that compliance with the regime is in their best interests. Taylor also discussed how the passive patient could also be viewed as abdicating their role in participation of their care. This abdication could be viewed as an escape from responsibility, disengagement from the process, or a form of denial.

Lynn (1993) found in researching her book on cancer treatments that we have gained little ground in the past several years in making the patient part of the health care team. Rather, we continue to see the patient as a passive participant who may be necessary for the process but whose individualism is not foremost in consideration. The medical professional does not request or solicit

patient input into the process. Their behavior does not create the opportunity for patient interaction. Lynn (1993) reviewed the various ways in which the medical profession maintains a power imbalance. Her contention is that the medical community, through technology advancements and terminology, has developed a wall between themselves and the patient. She views this distancing from the patient has been as detrimental to the professional as it is to the patient.

Education repeatedly is seen as the avenue for improving the patient's sense of control and empowerment. Newmann (1994) reports that patients' understanding of the procedures and illness impacting their lives is by far the most vital factor in determining their compliance and longevity on whatever form of treatment they choose. He recommends that educational efforts be continuous, imaginative and adaptive to accommodate the individual's needs and abilities, the long term nature of the illness, and the need to incorporate the patient into the health care team, in order to achieve optimal results in the delivery of dialysis.

Maire O'Donnell (1993) explores the manner in which hospice has already incorporated much patient empowerment language and policies into their daily interactions with patients and families. Their approach is patient driven from goal setting to treatment plans. Her conviction is that the adoption of a philosophy of patient empowerment

is vital, if health care staff are earnest in their attempts to empower patients. She identifies covert behaviors that continue to rob patients of the opportunity to embrace their own responsibility for their lives and maintains them in a passive role. Some examples of these behaviors are:

1. The goals for patient care are often set by nurses, instead of by the patient with the assistance of a nurse.
2. Colleagues often say that they work in a multi-disciplinary team when in fact each profession adheres to its own behavioral norms, and has difficulty communicating openly with others.
3. Managers (and practitioners) often talk about empowering others, giving them choice and delegating responsibilities, while telling others what they should be doing, retaining decision-making power and/or criticizing, and being judgemental in what has been called informal appraisal.

Oberle (1991) reported the link between compliance with medication regimes and the sense of control. Positively impacting the patient's compliance to the medication schedule, a sense of control was viewed as a tool for the medical profession wishing to impact on the patient's behavior. She found that patients who had a sense of control over their lives viewed their medication

schedule as their own responsibility. They viewed the schedule as a means to alter their environment in order to meet their needs. Those with a sense of helplessness and loss of control, viewed the medication schedule as an imposition of the health care team upon their lives and reminder of the illness. They did not incorporate the schedule into their daily routine as they viewed it as an intruder (Oberle, 1991). This would relate well to the work of Burger (1989) who found that our perceptions far outweigh reality in determining our behavior.

NEUTRAL/AMBIGUOUS RESEARCH

Ormel and Sanderman (1989) present an ambiguous position regarding empowerment. In their work related to control and depression, they identify the type of events or difficulties which appear to be most strongly linked to depression as loss events. The events described are highly consistent with the hemodialysis population, and thus, highly pertinent to this study. These losses include:

1. loss of physical abilities
2. loss of attachment figures
3. loss of significant peers
4. loss of social status or major source of social reinforcement
5. failures and disappointments

They acknowledge the recognition of the role of control in the onset of depressive disorders, but felt at that time, it was difficult to convincingly establish the role of control in regards to depression etiology.

Oberle (1990) also takes an ambiguous stance in evaluating her own study. Although, she found that a sense of control impacted the compliance with medication regimes, she also questioned the usefulness for this information in nursing practice. The ability to transfer knowledge gained from empowerment research into procedural and policy changes seemed to be the barrier. Oberle questions the ability to establish the sense of control through patient education. Once again the medical professional has the patient as the focus with patient change as the solution.

DISSENTING RESEARCH

Thompson (1981) discusses the impact of perception and meaning of the situation as it relates to the patient's perception of pain. Her findings were that the meaning of the event is far more important than the actual physical event. This would verify the previous discussion about perception of control being more significant that the actual level of control for the patient.

Thompson's argument continued that since it is such an individual response it would be impossible to develop programming changes to impact patients in a similar

direction. A counterpoint to this would be that although it is not possible to guarantee universal impact, one should continue efforts to impact as many as possible. Analogously, we cannot end world hunger today, yet we continue efforts to feed the poor. If through programming changes, empowerment can be generalized into the patient experience a proactive positive improvement over our present system would be seen.

Folkman (1982) addressed the possible negative impact that a perception of control may have on individuals. Her work emphasized the importance of the degree of control desired by the individual versus the degree of control they believe they have. Their findings were that when there is a discrepancy between the perception and the degree desired, the individual will experience heightened anxiety and decreased performance in many tasks. Although their work was quite impressive, there is question to its ability to transfer to the medical setting. Their experiments were conducted in controlled settings for a short period of time. These structured and contrived experiments cannot completely be replicated in the medical setting or with chronic conditions.

Waterworth and Luker (1989) performed a small study in which they determined that patients actually are under greater stress when control is placed in their hands. Their contention is that patients' passivity can be interpreted as a sign of their faith in their caregivers.

They discussed the power relationship in caregiving and suggested that to promote empowerment of the patients is to coerce patients into accepting something they do not wish to experience.

Their data revealed that some patients were more concerned with pleasing the nursing staff than in participating in their care. Their belief from these findings is that to encourage patient involvement would then be coercion and misuse of the power perceived to be held by the professional staff. This researcher feels that there are valid points raised in addressing the power imbalance between health care staff and patients and the ethical issue raised when attempting to alter this balance.

Concerns regarding this study must also be mentioned. The sample was extremely limited, the unstructured format of the interview process could result in wide interpretation of the data collected, and the location of the patients during the interview process (they were still inpatient in the facility in question) could also be viewed as a form of coercion. All these factors may have biased the results toward demonstrating a great deal of trust in health care staff and voicing little interest in gaining a sense of control.

Burger (1989) directs the question at the degree to which a person desires control. His premise is that when control given is greater than a person desires negative

behavior will result. His findings, although of great concern when one is considering procedural and policy changes to afford greater sense of control, did not result in a clear method of measuring the degree to which we need control. The highly individual nature of this battle would be extremely difficult to operationalize.

RESISTANCE TO EMPOWERMENT

There are other obstacles in the efforts to empower patients in health care. The American medical community has established a system of health care that allows little opportunity for the patient to gain a sense of control. With the advancement in technology and highly skilled mechanics involved with our healing process, many in the medical community would argue that the average individual is not capable of intelligently exercising his/her right of control (Waterworth & Luker, 1990). When the treatment procedure is highly technical and difficult to comprehend, can the patient make an informed decision or feel a sense of control? Certainly not without effort from the health care professionals with whom they choose to work.

Waterworth & Luker (1990) argue that in today's medicine, patients must exercise a large degree of trust in their caretakers and relinquish control to the experts. Patient oriented journals frequently carry articles with the emphasis on selection of caregivers. These articles are a frequent commodity as opposed to articles that would

enable the patients to have a better understanding of their illness and treatment process. They reinforce that responsibility lies with caregivers and patients can, at best, choose the "best" caregivers available.

There is also the resistance met when a group of people seek to gain control from another group who has enjoyed the position of power for some time. The resistance of the American medical community to relinquish its position of status, control, and power over the patient would also have to be addressed when attempting to alter the degree of empowerment of medical patients. The reality that many professionals do not realize the consequences of their actions is also a barrier to change. Before we can be motivated to alter our own behavior, we must acknowledge what we are doing and its impact.

Patients may also resist the opportunity to be empowered in the health care setting. To accept control brings with it the responsibility for their own health (Taylor, 1979). To assume control prohibits the patient from assuming a passive role. Accepting responsibility for our health is not a concept with great precedent in our society, and the long established deference to the medical community is difficult to breach for the lay person.

RESEARCH LIMITATIONS

Much of the literature focuses on the acute care population and is directed to the inpatient experience. The chronic hemodialysis experience differs significantly from these in that the loss of control is long term in nature and impacts on the patients' lifestyle in almost every facet of their lives. References to the chronic patient population consistently imply an increase in dysfunction, negative behaviors, or other adverse reactions. Studies (Mayer et al., 1989; & Brown & Furstenburg 1992) involving a chronic population have largely involved the nursing home resident. While there are some similarities to the hemodialysis population, there are significant differences also. No research specific to the chronic incenter hemodialysis population was found.

Prior to introducing policy and system changes in the health care setting, it will be of primary importance to clearly define that negative consequences for loss of empowerment exist. When asking professionals to buy into the idea of changing their approach to practice, it will be necessary to convince them of the risk for inactivity as well as the benefits in change.

SECTION III

METHODOLOGY

RESEARCH HYPOTHESIS

Will the loss of control or empowerment experienced by incenter hemodialysis patients result in adverse effects and negative behaviors? Will the schooling level of the patients play a role in their acceptance in the loss of control and therefore, impact on the occurrence of negative behaviors? My hypothesis is that a lack of empowerment in health care patients will result in adverse effects and negative behaviors. The behaviors to be monitored will be an increased perception of pain during treatment, depression, and noncompliance with the medical regime.

DEFINITIONS

Chronic renal failure is a progressive disease which impairs the kidney function to such a degree that medical intervention is required to prevent death (Daugirdas & Ing, 1994 -- See Glossary). Treatment options include:

1. Incenter hemodialysis
2. Peritoneal dialysis
3. Home hemodialysis
4. Transplantation

The first treatment modality is highly restrictive to the patient with diet, fluid, treatment schedule, and medication regimes which impact on the patient's lifestyle

and daily life. The renal diet is very complex and prohibits patients from eating many foods which are a staple to many diets. Fluid is restricted with patients allowed only 1000-2000 ml daily (King, 1991). Their treatment schedule is generally three times weekly for three to four hours at a time. Most patients are on numerous medications which serve as constant reminders of the chronic illness.

For the purposes of this study, the sample will be drawn from patients on incenter hemodialysis as they present a population profoundly lacking in empowerment. The goal will be to evaluate the impact that this loss of control may have on their behaviors.

Patients involved in peritoneal, home hemodialysis, and transplantation experience fewer restrictions and have a greater sense of control over their treatment. Patients who are chosen or choose to pursue these options have more control of their health care and experience a greater sense of empowerment than those on incenter hemodialysis.

Depression will be defined by:

1. A dysphoric mood
2. Loss of interest or pleasure in usual activities
3. Feelings of worthlessness or guilt
4. Thoughts of death or suicide

(see Glossary)

Other aspects frequently used in diagnosing depression are less reliable in the hemodialysis patient population as they are also symptoms of the disease process (Daugirdas & Ing, 1994). These would include loss of appetite, change in sleep pattern, and change in body image. Therefore, it is important to distinguish between physiological versus psychological causes.

Noncompliance will be defined as behavior not in keeping with the medical regime and which is physically detrimental to the patient in regard to fluid intake, medication schedules, and diet restrictions (see Glossary). This is evaluated by the health care team to insure that the cause is not related to lack of patient education/understanding or financial considerations. Once these barriers are determined to be nonexistent in the patient's situation, noncompliance is utilized as the nursing diagnosis.

The determination of noncompliance is based upon the monthly labwork done on each patient. These blood levels demonstrate whether the patient is taking particular medications as prescribed. Another objective gauge for compliance is the weight gained by patients between dialysis treatments. The goal of the fluid restriction is to maintain weight gains between dialysis treatments at three to six pounds. This restriction is, by far, the most difficult for patients to adapt into their lifestyle. Upon their arrival for treatment, all patients are weighed

and their weight documented in the medical records. Based upon the labwork and the weight increases, an objective measure of the compliance to treatment is possible.

Increased perception of pain during treatment will be defined as those patients who express to nursing staff that their treatment is painful to them. This procedure is not commonly considered painful. At times, related most often to noncompliance, patients may experience cramping and fluctuations in blood pressure. For the purposes of this study, patients experiencing pain related to *Steal Syndrome* (Daugirdas & Ing, 1994) will be factored out when monitoring this behavior (See Glossary). This syndrome can be quite painful and has an etiology unrelated to control.

SAMPLING

A judgment sample format was used in this study (Rubin & Babbie, 1993, pp.699). All patients who were currently dialyzing on the Dakota Medical Center outpatient unit as of December 15, 1994 were included. Only incenter hemodialysis patients were utilized as this treatment modality and regime is highly restrictive of the individual's lifestyle and choices.

Patients under the age of 21 were to have been excluded from the study since their developmental issues could have clouded the issue of control (Holman, 1983). As adolescents struggle for independence, differentiation,

and rebel against authority, their noncompliance issues differ from those patients over 21. At the time of sampling, there were no patients under the age of 21.

The age of patients ranged from 23 to 92. The average age of the patients was 62. The median age was 36, with the mode at 81. The sample was a fairly close blend of gender.

Gender	n	percent
Female	30	42
Male	42	58

The sample was largely homogenous with only 7 percent of the individuals falling into a category other than Caucasian. As previously discussed, cultural differences were examined to insure that noncompliance was not a result of language barriers and lack of understanding.

CULTURAL BACKGROUND	n
Native American	2
Hispanic	2
Vietnamese	1

PROCEDURE

A non-intrusive, exploratory, cross-sectional study was conducted utilizing existing medical records (Rubin & Babbie, 1993, pp. 107-110). Quantifiable data was extracted from the standardized nursing care plans and social histories from the medical records. Care plans that focus on pain, compliance with medical regime, and depression were monitored.

The independent variables were the chronic renal failure condition of each patient requiring them to undergo dialysis on a three time per week basis in the hospital setting and their educational level. The dependent variable was the diagnosis or notation of pain during dialysis treatment, depression, and compliance with the medical regime.

Standardized nursing care plans are a pre-printed form that defines the nursing response and protocol of care in reference to a specific diagnosis. Once the diagnosis is determined, an intervention responding to the patient need is designated and goal defined. These forms are completed on all patients receiving services on the outpatient unit and are located in a marked section of the medical record. The development and notation of these care plans are reviewed with patients monthly in an effort to afford an opportunity for patient involvement.

The care plans chosen to be monitored were:

Renal Team Diagnosis #3 -- Alteration in Comfort (notes increased perception of pain)

Renal Team Diagnosis #11 -- Diversional Activity Deficit (notes depression)

Renal Team Diagnosis #14 -- Impaired or Potential Home Maintenance Management (notes depression)

Renal Team Diagnosis #16 -- Noncompliance (notes behavior not in keeping with the medical regime)

(Appendix A, B, C, & D)

These care plans note the occurrence of the behaviors to be monitored in the study.

The schooling level of the patient is also found in the same marked section of the record in the patient's social history (Appendix E & F). Results were differentiated with the educational level of patients. The schooling categories were classified as follows:

1. Attendance through eighth grade or less
2. Attendance in high school through graduation
3. Attendance in some form of higher education whether technical school or college, for any period of time

The principal investigator conducted a chart review using a tally sheet (Appendix G). A highlighted notation on the care plan of the behavior being monitored resulted in a positive notation on the tally sheet. The results were separated into three areas:

1. Depression
2. Increased perception of pain during treatment
3. Noncompliance with the treatment regime

Confidentiality was protected with no patient identifiers on the data collected. As the data collection was accomplished in a non-intrusive manner patients were unaware of the study and thereby, unaffected by the process. This researcher felt this to be vital to respond to the concern regarding coercion and patient expectations. The study was approved by the Institutional Review Boards at both Augsburg College and Dakota Hospital.

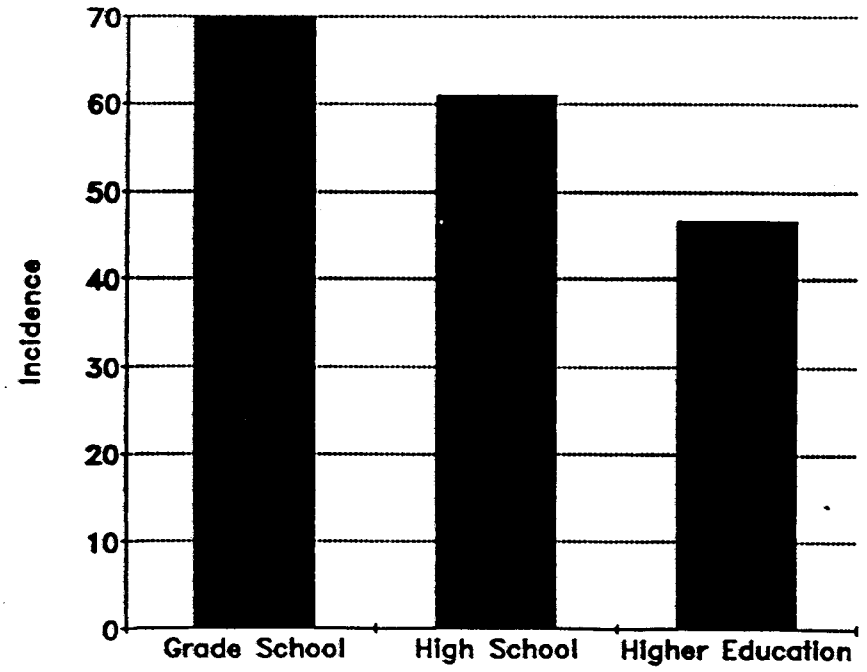
SECTION IV

STUDY FINDINGS

INCIDENCES

The incidence of having negative behavior in this population was significantly high. The overall incident rate of negative behaviors was 60 percent, with the incident range from 70 percent to 47 percent. Less education seemed to have an impact with that category having the higher incident rate (See Chart A). However, regardless of their level of schooling, all groups experienced a significant degree of negative behavior.

Chart A
Incidence of Negative Behaviors



The number of multiple responses varied between groups with the high school division having the highest number of negative behaviors.

SCHOOLING	n	# OF NEGATIVE RESPONSES
GRADE SCHOOL	20	14
HIGH SCHOOL	36	22
HIGHER EDUC.	15	7

DEPRESSION AND NONCOMPLIANCE

Frequency of behavior showed that depression and noncompliance were by far the most prevalent behaviors with increased perception of pain having few responses. Noteworthy in reviewing the behaviors exhibited by each respondent is the number who demonstrated both depression and noncompliance. As previously reported, research has demonstrated a link between the two behaviors with some belief in a causal relationship. This study, however, revealed 12 percent (n=5) of the sample demonstrated these behaviors occurring in tandem.

IMPACT ON SPECIFIC BEHAVIORS

The specific behavior also changed with the schooling level of the patient. Those with a higher education were more likely to struggle with noncompliance while those on

the other end of the spectrum dealt with depression more frequently.

SCHOOLING	PAIN	NONCOMPLIANCE	DEPRESSION
Grade school	3	5	10
High school	6	14	10
Higher Ed.	1	5	3

PERCEPTION OF PAIN

The incidence of increased perception of pain was quite limited with only 14 percent (n=10) of the patients demonstrating this behavior. Although a limited number, the human suffering that it reflects cannot be underrated. When patients must undergo a medical procedure they consider painful, three times a week for the rest of their lifetime, quality of life issues become paramount. Once again, the link to depression would be interesting to monitor.

DIFFERING RESULTS

The findings in this study did not support those of the earlier research (Mahler & Kulik, 1990) which found that individuals with a higher level of schooling struggled with the loss of control more than individuals with limited educational background. This investigator

was initially surprised by this findings until the supposition of the earlier researcher was examined in light of the sample utilized in this study.

Mahler & Kulik (1990) proposed that those with limited education had through their life experience given much control over to others in many aspects of their life. The supposition was that these individuals were working in factories and had their daily routine and activities controlled in many aspects by their employers and others. This ongoing relinquishing of control had, therefore, conditioned them to be more accepting of the loss of control experienced in the health care setting.

URBAN BIAS

However, when examining the current sample in this study (Social History -- Appendix E & F), an urban bias to the earlier findings could be suggested. The individuals with less schooling in this sample lived in a predominantly rural background. Although they had not attended high school, many felt that they had completed their schooling, as country school completed at grade eight. Many of these individuals went from eighth grade to running the family farm or working for others in farming. Some went to work in the local hardware store or manage the local gas station. Even those who worked for others felt a significant degree of autonomy in their daily lives, as their employers were quite often relatives

or close friends. The hierarchy of the factory worker's life (Mahler& Kulik, 1990), the loss of autonomy and freedom was not a frequent experience for those individuals in this rural sampling.

Many of the sample had little experience in giving control to others. The rural community in which this study was set, prides itself on self-sufficiency and autonomy. Many had little exposure to the health care community and prided themselves in "not being sick a day in my life 'till now". Many started dialysis and chronic treatment with no family doctor or significant health care professional identified with their family. They struggled with development of trust in a health care team which now seems to invade their life in so many aspects.

Those with a higher education levels tended to have had more exposure to the medical community. They were more likely to be able to identify their physician prior to the start of dialysis and had already developed some degree of trust in the medical team now caring for them. This group tended to work in a larger organization in which there was less autonomy. These individuals had experienced more relinquishing of control to others due to the hierarchies in which they labored.

IMPACT OF SCHOOLING

When examining the results of the three groups of patients (see Chart A) it appears that schooling may have an impact on the incidence of negative behaviors. The impact, however, does not appear to be significant enough to eliminate or reduce the frequency to an acceptable level. When the occurrence rate for the best group lies within the 50 percent range, we must examine other avenues than education in order to improve the results. The focus must turn from the patient to other dimensions.

SECTION V

IMPLICATIONS

INTERVENTION ALTERNATIVES

Efforts to provide support to patients in an attempt to enhance their coping with the multiple losses involved in this chronic illness are soundly based in our philosophy of practice. However, to stop there in our interventions is to reinforce the notion that the "problem" is patient centered.

Another perspective is program centered. What happens when a patient is introduced into the medical setting and labeled with a chronic illness that creates the situation where this behavior is so prevalent? What can we do systematically to prevent the behavior from occurring? Rather than taking a reactive approach to intervening with these negative behaviors, this researcher would suggest a proactive approach.

ECONOMIC PERSPECTIVE

Economically, the impact that empowerment offers should be of vital interest to our society. Reform and cost containment are at the forefront of any discussion regarding health care. Frequent hospitalizations, medical complications, increased mortality/morbidity, nursing home admissions, additional medications, and other manifestations of noncompliance impact on our society economically in significant numbers (King, 1991). The current climate of health care cost containment demands

that we address the fundamental needs which result in these spiraling costs.

The additional cost of staff time must also be factored when considering these behaviors associated with the loss of empowerment. Staff time dealing with noncompliance can range from re-instruction of patients regarding their diet, medications, and fluid restrictions, to additional dialysis treatments required due to fluid overload and high chemistries.

Depression resulting from the loss of empowerment also has a human toll. The emotional suffering of such a significant number of chronic renal failure patients has been addressed with psycho-tropic medications, psycho-therapy, and inpatient psychiatric admissions (Daugirdas & Ing, 1994). One contributing factor, the loss of empowerment, has not been addressed on any measurable level.

The human suffering experienced by those who endure a greater perception of physical pain in response to the loss of control must also be added into the cost column. Those who experience this perception of pain require additional staff attention and, often require prescription medications to deal with the pain.

To impact on these negative behaviors, calls for a process and philosophical change within the health care system.

SOCIAL WORK ADVOCACY

Social work has long been a leader in its efforts to empower the disenfranchised. We have long recognized the need for all individuals to have a sense of power and control over their lives. The positive impact that this has on individual ego strength and, thereby, the positive impact on the individual's behavior should move us to efforts to improve the patient's role in health care (Holman, 1983).

However, for too long, medical social workers have focused our energies on helping people cope with the loss of control through support. By taking this stance, we maintain the focus on the patient as the center of the problem. This researcher would propose that the medical social worker has, perhaps, bought into the health care system's mentality of control and left their patients' concerns and best interests behind. The status of the medical community in our society does not invite questioning of their methods or system. Social workers are no less affected by this mystique and the status of the medical community.

The role of social work has always been one of advocacy when dealing with institutionalized oppression of individuals. The health care setting provides an opportunity for social work to intervene in procedural and philosophic reform that would provide for the basic human need for empowerment and control (Mayer et al., 1990).

Procedures involved in admitting, treatment, and patient education should be closely examined by a multi-disciplinary team to insure language and intent to empower are conveyed in our interactions with the patient and family. The ethical and educational background of social work make it the most appropriate discipline to address these needs. Our experience with collaboration is conducive to the role of mediator during a procedural and policy evaluation process.

RESISTANCE

However, the existing role of social work in health care is focused on discharge planning and crisis intervention. With budgetary cuts, many hospitals are eliminating social work positions and limiting the workers activities. The ability to impact in a preventative manner and on a procedural level is becoming increasingly more difficult for the staff worker.

The medical profession could also present an obstacle to addressing this issue. To empower patients to take control over their lives will alter the previous balance of power in the relationship between medical staff and patient. Whenever a relationship changes the struggle to secure new footing between parties can result in stress. Medical professionals enjoy a rather paternalistic relationship at this time and may struggle with a change to equalize the relationship.

PROCEDURAL CHANGES

Hospital staff are quite committed to the concept of individualized patient care. However, for reasons of time, efficiency, and self-protection, actions do not always reflect this value. Staff fall back on protocols and procedures which depersonalize the care being given. The routinization of procedures accentuates the loss of patient identity by substituting formulas for personalized patient care.

The hospital bureaucracy places the patient in a complex structured organization which cannot be controlled by the patient. The patient becomes an object under the supervision of several different lines of authority with different division within each line (Taylor, 1979). As a result the patient may receive conflicting instructions and has little recourse or opportunity for clarification. Staff often deflect queries to another discipline. So where does ultimate responsibility lie?

Our language often depersonalizes the patient experience further. When interaction takes place in proximity to the patient, jargon acts as a shield to protect the patient from possibly upsetting news and the staff from being fully interrogated by the patient (Lynn, 1993). The terms often alarm and confuse the passive, but present patient. This does little to engage the patient in their care and elicit their valuable input into the process. Only the patient can provide their perspective

in the caregiving process, and yet, the medical community relies more heavily on lab results and technology to tell them if progress is being made.

This depersonalization, coupled with the disorientation that the illness itself may produce, creates a situation where passivity or rebellion is the common response. Staff convey the expectations of patient behavior to be cooperation, trust, and confidence (Taylor, 1979).

Many restrictions are instituted in the name of patient treatment regimes. The patient who is already feeling abused by the system is bound to rebel against what is viewed as further abuse of authority. If the restrictions were presented as options with explanations for their purpose, would rebellion be as frequent a response. Research has shown that when an individual views the withdrawal of freedom as arbitrary, the individual attempts to restore the lost freedoms (Taylor, 1979). If the regimes were presented to patients as options for their choice with complete information regarding consequences, patients would be less likely to view the situation as arbitrary and external.

Their elicited participation would carry with it a sense of responsibility for the decisions. By accepting a degree of responsibility, the patient takes ownership for their health care and becomes a partner to the process. A

partner would be handled differently by medical staff. Our choice of words in dealing with patients reflects our beliefs and values. When dealing with a partner, our presentation of patient education information would be slanted to reflect that partner status. Our words would solicit involvement, active participation, respect, and choice.

SECTION VI

STUDY LIMITATIONS

DEPENDENCE ON STAFF

The accuracy of the findings for this study are, of course, contingent on the accuracy of the staff documentation on the chart. The nursing staff is responsible for the completion of the standardized care plans and social workers are responsible for the completion of the social history. The accuracy of their observation was enhanced through staff education regarding the use of the standardized care plans.

SOCIAL HISTORY RELIABILITY

The accuracy of the social history information regarding the patient's level of education is relative to the trust between patient and social worker. Subjects are afforded privacy for the social history interview and few demonstrated any reserve in sharing their educational background. Those who had lesser education demonstrate little embarrassment or desire to keep this confidential. Many view the country school system that they completed as being very acceptable to their needs and quite customary for their region during that period of history.

PRE-EXISTING CONDITIONS

The inability to factor out pre-existing conditions also represents a limitation of the findings. It was not possible to diagnose the patients prior to their

initiation onto dialysis for the behaviors that were being monitored. Those patients studied may have experienced a period of depression, noncompliance with medical regime, and may have an increased perception of pain during any medical procedure.

It was not possible to diagnose these conditions prior to the initiation of dialysis, as it was equally impossible to determine if a pre-existing condition was worsened due to the intervention of dialysis. A patient suffering with a mild depression may, with the initiation onto dialysis find the depression deepening significantly. A person who may have been mildly noncompliant with medical instructions, may have found the highly restrictive lifestyle of a dialysis patient completely incompatible with their values and increase the self-destructive behavior of noncompliance.

CULTURAL DIFFERENCES

The sample for this study proved to be quite culturally homogenous. As the number of these individuals was so small, it would be impossible to determine if there were any significant differences based on ethnicity. Some work is currently underway in New York regarding ethnic differences in the area of noncompliance (Personal Communication, Bonnie Siegal, PhD, CSW, NASW Dip., January 24, 1995)

LACK OF BASELINE

Although this researcher feels confident that the 60 percent rate is significant, there is no baseline to compare the findings. It is not possible to identify patients prior to their diagnosis of chronic renal failure and, thereby, draw a baseline. One possible comparison for future studies may be to compare patients who have chosen different treatment options. Those on home dialysis who have a greater sense of control over their treatment could be compared to the incenter hemodialysis population.

RECOMMENDATIONS FOR FUTURE RESEARCH

Possible consideration should be given to a longitudinal evaluation of patients on dialysis and the impact time may have on the negative behaviors. The ability to adapt to loss and change over time may prove an interesting concept to monitor through research.

None of the research examined in preparation for this report demonstrated any differences or linkages between gender and response to loss of control. This issue may be worthy of consideration for future research.

If program and systemic changes could be implemented in the medical setting, it would also be prudent to examine the impact those changes had on patient behavior. Recommendation for a pre-test/post-test (Rubin & Babbie, 1993, pp. 701) would reveal the most pertinent data for

those attempting to enact changes to empower patients. The ability to convince medical professionals of the benefits to them and their patients could be enhance with findings from such a study.

CONCLUSION

The wide array of past research which has the patient centered approach does little to advance the medical community on the road to progress in this issue. To focus our energy on patient change, deflects the medical professional from having to address their own involvement in the depersonalization and disempowerment process of patients in health care.

To re-frame the issue and redefine the problem provides the health care system the opportunity to invoke <u>real</u> and substantial change. Given the current costs our society is incurring due to the loss of empowerment, it is in our best interests to pursue an option capable of impacting on the system overall. Empowerment of the patient is in keeping with the values of the medical community if not their actions. To reach congruence between their values and actions, will have a positive impact on the medical community, patients and families, and our society as a whole.

SECTION VII

APPENDIX A

DIALYSIS CARE _AN

Specific Diagnosis

ALTERATION IN COMFORT

Date/ Init.	Renal Team Diagnosis # 3	Goals	Target Date/ Date Met	Renal Team Intervention
	ALTERATION IN COMFORT			
RELATED TO	Pain Discomfort on run (cramps hypotension, chest pain) Anemia 2° renal failure Paresthesias Peritonitis	Patient will: -Obtain relief within one hour of taking medication. -Remain asymptomatic during run. -Experience fewer episodes of _____ _____during run...between runs. -Identify techniques that decrease pain and improve coping mechanisms. -Identify & reduce factors that precipitate or aggrevate pain. -Promptly report symptoms and follow treatment protocol. -Complete Patient Education Program.		Team will: -Assess symptoms. occurrences, degree of discomfort and relief measures. -Evaluate cause: fluid removed too fast, too much fluid removed, anti-hypertensive, medication schedule. -Provide baseline data related to pain behavior i.e., VS, grimaces. -Monitor Hct. -Provide symptomatic relief per renal protocols. -Provide and evaluate use of comfort measures. -Instruct patient on recognizing early symptoms to avoid a crisis. -Referral for pain control technique. -Present Patient Educatic Material. -Other _____
MANIFESTED BY	Pain behaviors: _____ _____ Verbal expression, states: _____ Symptoms of ↓ Hct SOB ↓ Energy level c/o ↑ weakness Symptoms of hypotension Burning, numbness, tingling in extremities.			

SIGNATURES/TITLE/INITIALS

DIETICIAN	SOCIAL WORKER	PRIMARY NURSE	OTHER
ADDRESSOGRAPH			

SPECIFIC DIAGNOSIS

ALTERATION IN COMFORT

DH 2485-05-89

APPENDIX B

DIALYSIS C. E PLAN

Specific Diagnosis

DIVERSIONAL ACTIVITY DEFICIT

Date/ Init.	Renal Team Diagnosis #11	Goals	Target Date/ Date Met	Renal Team Intervention
	DIVERSIONAL ACTIVITY DEFICIT			
RELATED TO	Time consuming treatments Change in lifestyle Lack of motivation/ depression Diminished socialization	Patient will: -Recognize feelings of boredom & discuss methods of finding activities. -Describe methods of coping with feelings of anger, depression caused by boredom. -Engage in an activity: _____ -State available community agencies that can be used for recreation. -Report feelings of improved self-esteem & productivity. -Complete Patient Education program.		Team will: -Encourage socialization with peers. -Increase person's feelings of productivity and self-worth by: a) Encourage patient to help others (give task if possible on unit). b) Acknowledge efforts made by patient. c) Encourage patient to challenge himself with learning a new skill or interest. d) Encourage communication showing value in patient's opinion -Provide list of available activities and organizations and motivate patient to seek these out. -Seat patient next to patient with positive attitude and talkative. -Offer Patient Education materials. -Other: _____
MANIFESTED BY	Constant expression of unpleasant thoughts or feelings Lethargy/anger Flat facial expression Restlessness C/O of nothing to do Patient states: _____ Other: _____			

SIGNATURES/TITLE/INITIALS

DIETICIAN	SOCIAL WORKER	PRIMARY NURSE	OTHER
ADDRESSOGRAPH			

SPECIFIC DIAGNOSIS

DIVERSIONAL ACTIVITY DEFICIT

DH 2493-05-89

APPENDIX C

DIALYSIS CARE PLAN

Specific Diagnosis

IMPAIRED OR POTENTIAL HOME MAINTENANCE MANAGEMENT

Date/ Init.	Renal Team Diagnosis #14	Goals	Target Date/ Date Met	Renal Team Intervention
	IMPAIRED OR POTENTIAL HOME	MAINTENANCE MANAGEMENT		
RELATED TO	Subclavian self-care Diabetic self-care CAPD self-care Chronic illness	Patient will: -Identify factors restricting self-care & home management. -Demonstrate ability to perform skills necessary for care at home, i.e. _____		Team will: -Assess patient & family for ability to perform task safely & correctly: _____ -Assess available resources. -Assess patient for impaired cognitive & emotional functioning. -Assist family & patient to acquire needed assistance at home. -Provide education for patient & family when additional assistance is needed: _____
MANIFESTED BY	Knowledge deficit: _____ Unavailable support system Sensory system deficit: _____ Impaired care giver Poor hygiene Inability to perform ADLs _____ (mobility, mental status, meals, housework, transportation) Inability to see one's own limitations Reluctance to look at other possible resources Lack of resources Other: _____	-Express satisfaction with home situations. -Maintain accurate records per protocol: CAPD Accucheck records -Maintain ability to live independently. -Use resources as appropriate to keep independent living situation. -Complete Patient Education program. -Other: _____		-Offer Patient Education materials. -Other: _____

SIGNATURES/TITLE/INITIALS

DIETICIAN	SOCIAL WORKER	PRIMARY NURSE	OTHER

ADDRESSOGRAPH

SPECIFIC DIAGNOSIS

IMPAIRED OR POTENTIAL HOME MAINTENANCE MANAGEMENT

DH 2496-05-89

APPENDIX D

DIALYSIS CARE PLAN

Specific Diagnosis

NONCOMPLIANCE

Date/ Init.	Renal Team Diagnosis #16	Goals	Target Date/ Date Met	Renal Team Intervention
RELATED TO	NONCOMPLIANCE Anxiety Negative side effects of treatments Unsatisfactory relationship with care giver Knowledge deficit Denial Lack of discipline Decreased self esteem Uremia Depression Poor memory & decreased mental acuity Other: _____	Patient will: -Identify manifestations of noncompliance: _____ -Verbalize cause & effect of noncompliant behavior. -State a substitute behavior that will minimize the non-compliant behavior. -Participate in decision making. -Express personal feelings related to noncompliance. -Exhibit compliant behavior, i.e. _____ -Record daily intake of food and fluid for evaluation by health team. -Complete Patient Education program.		Team will: -Initiate health teaching stressing importance of compliance to a prescribed regime. -Assess stress factors in patient's life that may contribute to non-compliance. -Assess for diagnosis powerlessness and alteration in coping. -Set up contract with patient for behavior modification. -Schedule care conference with patient: _____ date: _____ family: _____ -Evaluate patient record keeping. -Include patient in all treatment explanations. -Offer Patient Education materials. -Other: _____
MANIFESTED BY	Patient states: _____ Individual behaviors which fail to meet a prescribed treatment regime: _____ Abnormal chemistries per lab values: _____ Excessive weight gain:			

SIGNATURES/TITLE/INITIALS

DIETICIAN	SOCIAL WORKER	PRIMARY NURSE	OTHER
ADDRESSOGRAPH			

SPECIFIC DIAGNOSIS

NONCOMPLIANCE

DH 2498-05-89

APPENDIX E

DAKOTA HOSPITAL
DIALYSIS UNIT SOCIAL HISTORY

Name:_____ Transportation:_____

Address:_____ _____

_____ Pharmacy_____

Phone Number:_____ _____

EMERGENCY CONTACT:

Name	Relationship	Phone Number

FINANCIAL INFORMATION:

Medicare #_____ Effective_____

Other Ins.:_____ ID#_____

Prescription Coverage: Yes / No Understanding Billing: Yes / No

Source of Income:_____ Change since DX: Yes / No

Military Service: Yes / No Date Service:_____

FAMILY HISTORY:

DOB & Birthplace:_____

Education: 6 7 8 9 10 11 12 College Tech

Religion: Lutheran / Methodist / Catholic / Other_____ Marital Status: M / W / D / S

Parents: Mother_____ Father_____

City of Residence_____

SIBLINGS: Name	City of Residence
Spouse:	
Children:	
Other Significant Persons:	

LIVING SITUATION:

_____Lives Alone _____Own Home _____Lives with Spouse/Family _____Apartment

_____Nursing Home _____Other_____

HEARING: Good / Fair / Poor VISION: Good / Fair / Poor DRIVES: Yes / No STAIRS AT HOME: Yes / No

Addressograph

DH 3349-11-93

APPENDIX F

INDEPENDENCE WITH CARES:

_____Independent in ADL's_____ Receiving Services_____

_____Dependent on_____

_____DME needs_____ Referrals Needed_____

WORK HISTORY:

Current Occupation_____Hours/Wk_____

Previous Occupation_____

Retirement/Disability Due to CRF: Yes / No

Interest in Voc Rehab: Yes / No

Hobbies/Interests:_____

Medical History:_____

First Dialysis:_____ First Dakota run:_____

Understanding cause of CRF: Yes / No Options explored: Yes / No

Alterations since treatment started:_____

Concerns about TX: Yes / No_____

Compliance with diet/fluid/meds: Yes / No_____

Coping Skills:_____

Chemical use: (caffeine, cigarettes, alcohol, prescribed drugs, and street drugs)_____

History of: Anxiety Yes / No Depression Yes / No

Explain:_____

Assessment_____

GOALS AND RECOMMENDATIONS; Patient and/or Significant Other is in agreement.

1. Provide support to patient and family during initial adjustment period.
2. Assist with financial concern and educate regarding billing procedure.
3. Evaluate for home and community service referral needs.

Other:_____

Addressograph

Signature	Initials

DH 3349-11-93

APPENDIX G

TALLY SHEET

EDUCATIONAL LEVEL: _____ **GRADE SCHOOL OR LESS**

_____ **HIGH SCHOOL TO GRADUATION**

_____ **HIGHER EDUCATION OR VOCATIONAL**

STANDARDIZED CARE PLAN
(items chosen from standardized forms utilized on the dialysis unit -- positive findings on chart review will be reflected with a check on the space following the care plan title)

#3 Alteration in comfort _____

#11 Diversional Activity Deficit _____

#14 Impaired or Potential Home Maintenance Management _____

#16 Noncompliance _____

APPENDIX H

Rec. 12/1/94

REQUEST FOR EXEMPTION FROM COMMITTEE REVIEW OF RESEARCH INVOLVING HUMAN SUBJECTS

1. **Project Title:** (Use same title as grant application, if applicable)

Patient Empowerment and Chronic Hemodialysis

2. **Principal Investigator** Laurie K. Dahley, LSW
(first mi last degree)

Telephone number (701)282-6939 wk-(701)280-4783

College department name Master of Social Work

Investigator's address 1030 2nd St. West
West Fargo, ND 58078

(For IRB Use Only)
Approval #: 94-24-1

3. **Check one:**

____ Faculty / staff research
____ Fellow / post doctoral
_X_ Student Research
____ Undergraduate
_X_ Graduate

4. **If principal investigator is a student:**

Advisor's Name: Blanca-Rosa Egas
Address: 731 21st Ave. So.
Minneapolis, MN 55454
Telephone (612)330-1713

5. Applications for approval to use human subjects in research require the following assurances and signatures to certify:

- The information provided in this application form is correct.
- The Principal Investigator (PI) will seek and obtain prior written approval from the IRB for any substantive modification in the proposal, including, but not limited to changes in cooperating investigators, agencies as well as changes in procedures.
- Unexpected or otherwise significant adverse events in the course of this study will be promptly reported.
- Any significant new findings which develop during the course of this study which may affect the risks and benefits to participation will be reported in writing to the IRB and to the subjects.
- The research may not be initiated until final written approval is granted.

This research, once approved, is subject to continuing review and approval by the IRB. The PI will maintain records of this research according to IRB guidelines.

If these conditions are not met, approval of this research could be suspended.

Signature of Principal Investigator Laurie Dahley Date 11-25-94

Student Research: As academic advisor to the student investigator, I assume responsibility for insuring that the student complies with College and federal regulations regarding the use of human subjects in research:

Signature of Academic Advisor B. Egas Date 11/28/94

Faculty/Staff Research: As department chair, or designed, I acknowledge that this research is in keeping with the standards set by our department and assure that the principal investigator has met all departmental requirements for review and approval of this research.

Signature of Department Chair Rosemary Link Date Dec 1 '94

Signature of IRB Chair Joseph A. Erk Date 12/13/94

1

GLOSSARY

Chronic Renal Failure -- The slow destruction of normal kidney tissue that occurs over months or years and results in End Stage Renal Disease. At this stage of kidney impairment, dialysis or transplantation are the medical treatments necessary to maintain life and health.

Depression -- the most common mental health complication experienced by hemodialysis patients. It is manifested by persistent depressive mood, a poor self-image, and feelings of hopelessness. Physical complaints are not unusual and include sleep disorder, change in appetite and weight, dryness of the mouth and constipation, and decrease in sexual interest and ability. However, with end stage kidney disease, many of these physical symptoms also have a physiolog[ical cause which must be addressed prior to making the diagnosis of depression. Uremic symptoms often mirror depression and it would be wise to insure that the patient is adequately dialyzed prior to beginning treatment for depression.

Hemodialysis -- The use of an artificial kidney machine to maintain the fluid and chemical balance of the body when kidney function has deteriorated to End Stage.

Noncompliance -- any behavior that a patient engages in that is in direct opposition to medical advice and that results in direct negative impact on that patient's health. This can be objectively monitored by monthly labwork which includes a chemistry panel. Examples of noncompliant behavior would be the failing to take prescribed medications even in the face of adverse effects, drinking more that 8 pounds of fluid between treatments, or consuming food high in potassium.

Peritoneal Dialysis -- A process in which dialysate solution is drained in and out of the abdominal cavity. The peritoneal membrane in the abdomen functions in the same way that the cellulose membrane does in the artificial kidney.

Steal Syndrome -- This syndrome is caused by ischemia of the hand when compromised circulation results from the placement of an internal access device. This internal access device is utilized to gain access to the blood in order to perform dialysis. If blood circulation is poor in the extremity, some patients will experience pain, a cold clammy feeling, and in some cases, the appearance of nonhealing ulcers.

Transplantation -- The surgical procedure that involves taking an organ from a cadaver or from a living donor and implanting it in a patient.

REFERENCES

Black, R. (1989). Challenges for social work as a core profession in cancer services. Social Work in Health Care, 14(1), 1-14.

Brown, J. & Furstenberg, A. (1992). Restoring control: Empowering older patients and their families during health crisis. Social Work in Health Care, 17(4), 81-101.

Burger, J. (1989). Negative reactions to increases in perceived personal control. Journal of Personality and Social Psychology, 56(2), 246-256.

Cohen, J. & Tucker, C. (1994). Denial and depression as quality of life factors in hemodialysis patients. Contemporary Dialysis & Nephrology, May, 22-25.

Daugirdas, J. & Ing, T. (1994). Handbook of dialysis. Boston, Mass.: Little, Brown and Company.

Eddins, B. (1985). Chronic self-destructiveness as manifested by noncompliance behavior in the hemodialysis patient. Journal of Nephrology Nursing, July/August, 194-197.

Evans, R. (1994). Quality of life in end-stage renal disease: Practical issues in assessment. Dialysis Reports, 1994.

Folkman, S. (1984). Personal control and stress and coping processes: A theoretical analysis. Journal of Personality and Social Psychology, 46(4), 839-852.

Hepworth, D.H. (1993). Managing manipulative behavior in the helping relationship. Social Work, 38(6), 674-682.

Holman, A. (1983). Family assessment: Tools for understanding and intervention. Newbury Park, CA: Sage.

King, K. (1991). Noncompliance in the chronic dialysis population. Dialysis and Transplantation, 20, 67-68.

Lynn, J. (1993). Don't tell the patient. Nursing Standard, 7, 50-51.

Mahler, H., & Kulik, J. (1990). Preferences for health care involvement, perceived control and surgical recovery: A prospective study. Social Science Medicine, 31, 743-751.

Mayer, J., Kapust, L., Mulcahey, A., Helfand, L., Heinlein, A., Seltzer, M., Litchfield, L., Levin, R. (1990). Empowering families of the chronically ill: A partnership experience in a hospital setting. Social Work in Health Care, 14(4), 73-90.

Miller, S., Christopher, C., & Stoddard, E. (1989). Information, coping and control in patients undergoing surgery and stressful medical procedures. In H. Lefcourt (Ed.) Research with the locus of control construct. (pp.107-130) New York: Academic Press.

Newmann, J. (1994). Education and Patient Empowerment. Nephrology News and Issues, July, 22-27.

Oberle, K. (1991). A decade of research in locus of control: what have we learned? Journal of Advanced Nursing, 16, 800-806.

O'Donnell, M. (1993). How to enable staff to empower patients. Nursing Standard, 8, 38-39.

Ormel, J., & Sanderman, R. (1989). Life events, personal control and depression. In H. Lefcourt (Ed) Research with the locus of control construct. (pp.193-212) New York: Academic Press.

Rubin, A. & Babbie, E. (1993). Research methods for social work. Pacific Grove, CA: Brooks/Cole.

Singleton, J. (1994). Nutrition and health education for limited income, high-risk groups: Implications for nutrition educators. Journal of Nutrition Education, 26(3), 153-155.

Smith, R., & Draper, P. (1994). Who is in control? An investigation of nurse and patient beliefs relating to control of their health care. Journal of Advanced Nursing, 19, 884-892.

Taylor, S. (1979). Hospital patient behavior: Reactance, helplessness, or control? Journal of Social Issues, 35, 156-184.

Thompson, S. (1981). Will it hurt less if I can control it? A complex answer to a simple question. Psychological Bulletin, 90, 89-101.

Wallston, K. (1989). Assessment of control in health-care settings. In A. Steptoe & A. Appels (Eds.) Stress, personal control and health. (pp. 85-105), West Sussex, UK: Wiley & Sons.

Wallston, K., & Wallston, B. (1981). Health locus of control scales. In H. Lefcourt (Ed) Research with the locus of control construct. (pp. 189-243) New York:Academic Press.

Waterworth, S., & Luker, K. (1990). Reluctant collaborator: Do patients want to be involved in decisions concerning care? Journal of Advanced Nursing, 15, 971-976.